Original Article

Iranian Nurses' Perceptions of the Conditions of the Families with Terminally Ill Patients: Family in Limbo

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Background: Understanding the conditions of terminally-ill patients' family members is the first step in reducing their emotional distress. **Objectives:** The aim of this study was to explore nurses' perceptions of the conditions of terminally ill patients' families. Methods: This qualitative content analysis study was conducted in 2016–2017. Participants were 24 nurses purposively recruited from 14 hospitals in Tehran, Iran. Data were collected through semi-structured interviews and analyzed through conventional content analysis, Results: Participants' perceptions were categorized into two main categories, namely, behavioral and emotional turmoil and perceived worries. The two subcategories of the first category were family turmoil after receiving bad news and family members' violent behaviors after receiving bad news. The second category included four subcategories, namely, feeling guilty, worries about patient's fate, worries about the aggravation of patient's conditions, and financial worries. The main theme of the study was family in limbo. Conclusion: Terminally ill patients' family members are in limbo due to behavioral and emotional turmoil and different worries. Nurses can use the findings of this study to help terminally ill patients' family members undergo a healthy grief.

KEYWORDS: End-of-life care, Family, Nurse, Qualitative research

Introduction

urses often encounter families who suffer from the imminent loss of one of their members. These families need to deal with a wide variety of duties and experience different negative psychological problems in the process of caregiving to their terminally ill patients. Such a condition makes families emotionally fragile. Thus, nurses need to provide them with quality cultural and ethical care in order to restore their emotional well-being. This type of care can be provided in light of artistic interaction with families and proper understanding of their conditions.

Assessment of families to understand their conditions in the terminal life stages of their ill members is a prerequisite to provide them with quality care. Such assessment and understanding enable nurses to identify families' needs and conditions, [8] reduce families' emotional strains, [9] and improve care quality, families' mental health, and families' decision-making ability. [10]

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On the contrary, nurses' inadequate understanding of families' emotional conditions can cause families' varying levels of stress, anxiety, and helplessness.^[11]

Previous studies on terminally ill patients' families mainly focused on their physical and emotional suffering^[12,13] and their psychological problems before and after the death of their patients.^[13-15] Similarly, studies in Iran dealt mainly with the experiences of the family members of the patients with vegetative status^[16] and the psychological needs of the family caregivers of dying cancer patients.^[17] Hence, there is a wide knowledge gap regarding nurses' perceptions of the conditions of families with terminally ill patients. On the other hand, given the patient-centered approach to

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care delivery in most health-care centers in Iran, [18] the main concern of the nurses who provide end-of-life care seems to be patient management and hence terminally ill patients' family members and their needs are usually taken for granted. [19] The present study was conducted to fill these gaps.

Objectives

The aim of this study was to explore nurses' perceptions of the conditions of families with terminally ill patients.

Methods

Research design, participants, and setting

This study was conducted using an inductive qualitative content analysis. This design was chosen due to the paucity of information about the study subject matter.[20] Participants were selected through purposive sampling with maximum variation in order to ensure the inclusion of different viewpoints in the study. Selection criteria were a clinical work experience of at least 2 years in dealing with the families of terminally ill patients. Accordingly, 14 male and 10 female nurses were selected from different hospital wards, namely, oncology care wards (n = 5), emergency departments (n = 4), intensive care units (ICUs) (n = 7), coronary care units (n = 3), neonatal ICUs (n = 1), medical units (n = 3), and transplantation units (n = 1). Participants held bachelor's (n = 15), master's (n = 7), or Doctor of Philosophy (n = 2) degrees and were working as staff nurses, head nurses, or charge nurses. The study setting consisted of 14 hospitals in Tehran, Iran, with wards and units for providing care to terminally ill patients.

Data collection

Data were collected from March 2016 to February 2017 through face-to-face in-depth semi-structured interviews. All interviews were conducted in Persian by the first author in a quiet room in participants' preferred places. Each interview began using a broad question, "May you please tell me about your experiences of the emotions and the feelings of families with terminally ill patients?" Subsequently, other broad and probing questions were asked to collect more in-depth data. These questions included "What do you mean by this?" "Could you explain more about this?" and "How did you understand that the family felt guilty after receiving bad news about their patient's conditions." Interviews lasted 30 min, on average. All interviews were audiotaped and transcribed verbatim. Sampling and data collection were continued up to data saturation.[21]

Ethical considerations

This study was approved by the Ethics Committee of Tarbiat Modares University, Tehran, Iran (approval code:

52D.9109). Participants were informed about the study aim and the voluntary participation in the study, and then, personal informed consent was obtained verbally from each of them. We also attempted to collect genuine data and protect participants' identity through allocating a numerical code to each interview. Moreover, the confidentiality of the data was guaranteed through not discussing interview content with others.

Data analysis and trustworthiness

Data analysis was carried out manually and simultaneously with data collection using Graneheim and Lundman's conventional content analysis. After reading each interview transcript for several times and grasping its main ideas, the words, sentences, and paragraphs which were relevant to the study aim were extracted as meaning units. Then, these meaning units were abstracted and labeled as codes. The generated codes were categorized according to their similarities and differences into subcategories and categories. Finally, the main theme of the study was extracted to describe the latent content of the data [Table 1]. [22]

Trustworthiness was applied to the study using the criteria proposed by Lincoln and Guba. [23] Credibility was established through prolonged engagement with the data and member checking. In member checking, several interview transcripts together with their related primary codes were provided to participants to check if our generated codes accurately reflected their experiences. Moreover, dependability was applied through peer checking, during which coauthors reviewed and confirmed the accuracy of data analysis. To ensure confirmability, all steps of the study were clearly described for the purpose of external auditing. Finally, transferability was ensured through maximum variation sampling respecting participants' gender, educational levels, and work experience.

RESULTS

Nurses' perceptions of the conditions of terminally ill patients' family members were conceptualized as "family in limbo." As presented in Table 1, this main theme included the two main categories of behavioral and emotional turmoil and perceived worries.

Behavioral-emotional turmoil

According to the participants, the families of terminally ill patients are in a state of great confusion and emotional disturbance and experience intense emotions, which affect their physical and behavioral status. Behavioral and emotional turmoil reflects families' mental involvement after receiving bad news about their patients' critical conditions. Participants highlighted that

Table 1: Nurses' perceptions of the conditions of terminally ill patients' family members				
Meaning units	Codes	Subcategories	Categories	Theme
In the evening, we heard screaming and wailing. She was a girl who was just scratching her face. She was afraid. She said my mother! How is this possible? The girl had a terrible condition at that time	Wailing and cries after being informed of the patient's conditions Self-harm after being informed of the patient's conditions	Family turmoil after receiving bad news	Behavioral and emotional turmoil	Family in limbo
	Fear after being informed of the patient's conditions			
After the father heard the child was dying, he kicked the door hard and broke it. His behavior was very bad	Inappropriate behavior after being informed of the patient's conditions Destructive behavior after being	Family members' violent behaviors after receiving bad		
He was a son who had abandoned his father for a few years. Then, when he found out his father was dying, he felt really guilty. When he came to see his father, he became agitated and created a lot of controversies. He blamed me for his father's conditions. It was all because he was blaming himself	informed of the patient's conditions Feeling guilty due to negligent behaviors toward the patient	news Feeling guilty	Perceived worries	
	Blaming hospital staff for their inability to save the patient			
They were worried about the future and about what was going to happen to them, what would happen tomorrow, and what would happen next. It was very difficult for them	Worries about indefinite future Worries about having no control over events	Worries about patient's fate		
The suddenness of the event made the family very agitated. The patient was a child, like the other children. His hand was bruised somewhat and he had suddenly been diagnosed with leukemia	Agitation due to an unexpected situation	Worries about the aggravation of patient's conditions		
	Agitation due to the unexpected diagnosis of severe disease			
Because the family was unable to pay the costs of hospitalization in a private hospital, they had no option but to transfer the patient to a public hospital. This had doubled the suffering of the family	Inability to pay for hospital fees Exacerbation of the suffering of the family due to financial problems	Financial worries		

terminally ill patients' families experience emotional and behavioral disturbances after receiving bad news such as brain death, patient's vegetative status, patient preparation for organ donation, likelihood of death, unsuccessful cardiopulmonary resuscitation, and patient death. Our participants noted that in their settings, terminally ill patients' families had sometimes been informed about their patients' conditions by expressions, such as "The disease may recur," "Everything is useless for your patient," "Don't expect miracles for your patient," "There is no higher chance of recovery by taking the patient to other centers," "Patient's life depends on medications and equipment," and "The patient may die despite medications." Participants' perceptions of the behavioral and emotional turmoil of terminally ill patients' family members were categorized into two subcategories, namely family turmoil after receiving bad news and family members' violent behaviors after receiving bad news.

Family turmoil after receiving bad news

After receiving bad news about their patients' terminal conditions, family members experience emotional

problems such as agitation, fear, desperation, depression, and crying. Remembering an emergency situation, an emergency-room nurse said: "It was an emergency situation and patient's family members were agitated. When they saw their patient was on the bed with critical conditions, they became more agitated. Thus, they did not understand what I was saying to them and just wanted to get rid of that situation. It was very annoying to the family" (P 2). An intensive care nurse also described a mother whose son had been diagnosed with cancer: "When the mother saw that her son was in bad conditions, she became overwhelmed, distressed, and quite pale. She really didn't know what to do. She just cried. Her conditions were so disturbing that I really couldn't control myself and hugged her and started crying. She also tightly grasped my hands and cried. I really couldn't understand her feelings" (P 19).

Family members' violent behaviors after receiving bad news

Nurses frequently commented that, after receiving bad news about their patients' terminal conditions, some family members may show violent behaviors such as damaging equipment, verbal threat, insult to nurses, and quarrel with them. A pediatric oncology nurse said: "She suddenly lost her control. After she returned to her normal conditions, she found that she had broken ICU windows. She apologized. But, when she heard her child was dying in ICU, she completely lost her control" (P 10). An emergency-room nurse also commented in this regard: "He came inside and shouted loudly, "You want to kill my brother." He threatened to kill us. We asked him to wait. Then, we got into a fight. I attempted to prevent him from taking any physical action, but he insulted me and started talking trash. He used a lot of foul language and even used the "f" word. He just wanted to hit me" (P 21).

Perceived worries

Besides understanding emotional disturbances of terminally ill patients' families, our participants reported a set of annoying emotions which indicated worries in families. The four subcategories of this category were feeling guilty, worries about patient's fate, worries about the aggravation of patient's conditions, and financial worries.

Feeling quilty

Participants noted that in the last days of terminally ill patients' lives, their families show reactions that are indicative of their feeling of guilt. These reactions include going through fire and water to save their patients' lives, asking nurses to administer less painful treatments, and even requesting the discontinuation of life-saving therapies in order to alleviate patients' suffering. Such feeling of guilt is due to factors such as neglectful behaviors toward patients in the past or witnessing their suffering as a result of treatments. An oncology nurse said: "At that moment, family members were in a situation that they wanted to do whatever they could for their patient. Two days later, they saw that their patient was under ventilator. However, they didn't feel any improvement in patient's conditions. Thus, they felt guilty over consenting to such painful treatments for their patient and asked me to disconnect the patient from the ventilator and remove tubes from the patient's body. They even threatened that they would remove tubes themselves if I refrained. Such behaviors were due to their emotional distress" (P 11).

Worries about patient's fate

Worries over patient's indefinite future, lack of control over patient's conditions, recurrence of patient's problems, and occurrence of unexpected events can cause distress, anxiety, and confusion for family members. A nurse in the transplantation unit said: "Family members repeatedly ask me about the future of

their patient. They ask me if it is ok to take their patient to another doctor" (P 12).

According to participants, family members' worries over their patients' indefinite future make them feel intense emotions, reduce their rational thinking ability, and cause them decisional uncertainties. A coronary care nurse said: "Family members were in a real perplexity. They didn't know whether let their mother die or donate half of her life to another patient., they were between denial and acceptance and couldn't make their final decision" (P 24).

Worries about the aggravation of patient's conditions

Our participants noted that while family members expect improvements in their patients' conditions, sudden deterioration of patients' conditions causes worries for them. Most family members continuously strive to save their patients at any cost. They seek information about their patients' conditions, treatments, and prognoses through the families of the patients with similar conditions or from the Internet. However, information seeking is associated with greater worries about patient's conditions and greater uncertainties about the final decision. A pediatric oncology nurse said: "A mother insisted that she liked another doctor to visit her daughter because she wanted to save her. I talked to her a lot; but it was futile. Thus, I talked to the head of our department to change the patient's doctor. Subsequently, the chemotherapy protocol was changed. Two weeks later, the mother told that she wanted the first doctor. She justified her new decision by saving that the new chemotherapy regimen had caused her daughter greater suffering and pain" (P 9).

Financial worries

According to our participants, the family members of terminally ill patients have many financial worries because of factors such as their inadequate income, incomplete insurance coverage, additional costs associated with patient visits by others, and employment loss due to the need for permanent presence in medical centers. On the other hand, they may have worries over damages to their families' dignity and honor due to financial assistance provided to them by health-care centers or charities. Patients' long stay in hospital also causes financial worries for some families and may eventually require them to decide on treatment discontinuation. An intensive care nurse commented: "We had a patient in ICU whose family did not have a good financial status. The family was no longer able to afford their patient's treatments and ICU stay. Thus, family members asked us to disconnect their patient from ventilator and discontinue treatments" (P 1).

DISCUSSION

Nurses' perceptions of the conditions of terminally ill patients' family members were conceptualized as family in limbo. In Persian literature, limbo figuratively refers to disturbance, anxiety, confusion, sadness, dissatisfaction, and anger. [24] The Cambridge Dictionary also defines limbo as a situation, in which a person is located between two stages with an indefinite future or an uncontrollable uncertain situation. [25] It is also used to refer to the world between this world and the hereafter, but neither the heaven nor the hell. [26] Moreover, it is defined as anxiety, worry, inertia, frustration, anger, and fear. [27]

Behavioral and emotional turmoil was one of the two main categories in this study. It refers to nurses' perceptions of the emotions and the behavioral reactions of terminally ill patients' family members in response to bad news about their patients' conditions. Similarly, a former study reported that witnessing patient's suffering worsens family members' emotional pain and loss experience. [28] Our findings also showed that participating nurses had encountered families which were in shock, perplexity, and confusion after receiving bad news about their patients' conditions. In agreement with this finding, an earlier phenomenological study showed that families experienced bewilderment and shock in case of their patients' brain death.[15] We also found that unexpected changes in patients' conditions, administration of new treatments, and recurrence of health-related problems make family members more disturbed, confused, sad, anxious, and impatient. In line with these findings, a study found that the family members of terminally ill patients experienced anxiety, sadness, uncertainty, guilt, anger, despair, and loneliness. [29] Moreover, our participants had perceived fear and frustration among terminally ill patients' family members. Fear disturbs family members' lives and reduces their ability to cope with the reality of their patients' death. [30]

Our findings also showed violent behaviors among family members after receiving bad news about their patients' conditions. A study showed that family members in most Middle East countries see hospitalization as a great misfortune, tragedy, and possible death. [31] Bad news about patients' conditions causes anger for patients' family members and requires them to make unreasonable requests from health-care providers. Different from our findings, a study reported that family members may feel angry if they are not informed about their patients' conditions. [32] Moreover, a study into the challenges experienced by nurses in dealing with brain-dead patients suggested that family members often blame nurses and roughly treat them when they are not

well informed about their patients' conditions.^[33] This difference among the studies is attributable to the fact that our study did not aim to assess nurses' challenges in the process of care delivery; rather, it explored nurses' perceptions of the conditions of terminally ill patients' family members.

Another finding of the study was that terminally ill patients' family members sometimes blame themselves or nurses and also feel guilty due to their inappropriate behaviors toward their patients in the past and losing the golden opportunity to take care of their beloved ones. Similarly, a study indicated that continuous self-blame for what is happening to a dying patient is associated with the feeling of guilt.[30] Moreover, our participants perceived financial problems among terminally ill patients' family members due to the high costs of hospitalization. Financial problems can give family members' feelings of helplessness and anxiety and thereby cause them emotional and social problems. Family members in Iran have close emotional ties with each other and hence the serious conditions of one of them can exert devastating effects on the others.^[34] We found that financial problems may eventually make family members' request for treatment discontinuation. This finding denotes that in case of a terminally ill patient, family members' worries about hospitalization costs overweigh the loss of their patient. In agreement with this finding, a study showed that financial burdens on family members make them prefer comforting care over life-extending care.[35] According to the existing evidence, most insurance companies in Iran do not pay for end-of-life care; thus, terminally ill patients' family members may resort to their savings, apply for loans, or seek a second job to afford hospitalization costs. [36]

The other findings of the present study were families' worries about their terminally ill patients' indefinite future due to the likelihood of unexpected events or unexpected treatment outcomes. Similarly, a former study reported that ambiguities about treatments and prognosis lead to uncertainties for family members. Simultaneously, postponing medical treatments to see the effects of current treatments may cause undue pain and suffering for family members.^[37]

One limitation of this study was related to sampling in only one city. Replication of this study in other cities can provide more conclusive evidence respecting nurses' perceptions of the conditions of terminally ill patients' family members. Another limitation was related to the lack of differentiation between nurses' perceptions of the conditions of family members of patients with acute and chronic health problems. Therefore, studies are needed to address this limitation. Moreover, we recommend

studies to develop a valid and reliable instrument to measure the conditions of terminally ill patients' family members

CONCLUSION

Emotional turmoil and perceived worries associated with the critical conditions of terminally ill patients place their family members in limbo. Family in limbo, the main theme of the study, reflects nurses' perceptions of emotional vulnerability in terminally ill patients' families. These findings contribute to the body of knowledge of nursing and can help develop effective family care plans for these families. Placement in limbo may expose family members to a pathologic grief. Thus, nurses need to develop and use preventive measures based on family members' conditions and needs in order to help them undergo a healthy grief.

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Conflicts of interest

There are no conflicts of interest.

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